

Injustice perceptions about pain: Parent-child discordance is associated with worse functional outcomes.

Megan M. Miller^a, David Wuest^a, Amy E. Williams^b, Eric. L. Scott^c, Zina Trost^d, Adam T. Hirsh^a

Institutional Affiliations

^aDepartment of Psychology, Indiana University-Purdue University Indianapolis, 402 N. Blackford St. Indianapolis, Indiana 46202, Email: mmm24@iupui.edu

^bDepartment of Psychiatry, Indiana University School of Medicine, Riley Hospital for Children, 705 Riley Hospital Dr. Indianapolis, Indiana 46202, Email: amyewill@iupui.edu

^cDepartment of Pediatrics and Anesthesiology, University of Michigan, C.S. Mott Children's Hospital, 1540 E. Hospital Dr. SPC4228 Ann Arbor, Michigan 48109, Email: erlscott@med.umich.edu

^dDepartment of Psychology, University of Alabama Birmingham, 1720 2nd Ave S Birmingham, Alabama 35233, Email: ztrost1@uab.edu

Corresponding Author

Adam T. Hirsh, PhD, Department of Psychology, LD124, 402 N. Blackford St., Indianapolis, IN 46202, Phone: (317)-274-6942 Fax: (317)-274-6756 Email: athirsh@iupui.edu

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Abstract

Pain is experienced in and influenced by social environments. For children with chronic pain, the child-parent relationship and parental beliefs about pain are particularly important and may influence pain outcomes. Pain-related injustice perceptions have recently been identified as an important cognitive-emotional factor for children with pain. The current study aimed to better understand the pain-related injustice perceptions of children with chronic pain and their parents. The sample consisted of 253 pediatric chronic pain patients (mean age=14.1 years, 74% female) presenting to a tertiary pain clinic. Patients completed measures of pain intensity, pain-related injustice perceptions, stress, functional disability, and quality of life. Parents completed a measure of pain-related injustice perceptions about their child's pain. Child-parent dyads were categorized into one of four categories based on the degree of concordance or discordance between their scores on the injustice measures. One-way ANOVAs examined differences in pain intensity, stress, functional disability, and quality of life across the four dyad categories. Our findings indicated that both the degree (concordant vs. discordant) and direction (discordant low Child – high Parent vs. discordant high Child – low Parent) of similarity between child and parent injustice perceptions were associated with child-reported pain intensity, stress, functional disability, and quality of life. The poorest outcomes were reported when children considered their pain as highly unjust but their parents did not. These findings highlight the important role of parents in the context of pain-related injustice perceptions in pediatric chronic pain.

Keywords: perceived injustice, parent, child, adolescent, quality of life, functional disability, chronic pain

Introduction

Pain is experienced within and influenced by social environments, demanding attention from both the sufferer and proximal others[2,6,7,11,15,45]. For children with chronic pain, the child-parent relationship is of particular importance. Parents often serve as secondary reporters on children's pain. Studies have highlighted similarities and differences in child-parent reports of pain intensity[1,10,49], functioning[5,10], and treatment expectations[10,32], as well as the impact of child-parent discordance in these domains on treatment approach and adherence[10,32].

Given their prominent role as caregivers, it is natural that parents develop their own set of beliefs about their child's pain. Studies have found parental appraisals, such as catastrophizing, can influence pain outcomes[23]. High parental catastrophizing about their child's pain is associated with greater pain intensity, school absences, and functional disability[19,12,20]. Moreover, studies suggest that the degree of concordance between parent- and child-reported catastrophizing influences outcomes. Lynch-Jordan and colleagues[21] found that child functional disability and depressive symptoms were highest among child-parent dyads consisting of a high catastrophizing child and low catastrophizing parent in a sample of children with varying pain conditions. Among children with sickle cell disease, Sil and colleagues[35] also found child-parent discordance was associated with poorer outcomes. However, they found a different pattern than Lynch-Jordan, such that dyads with *low* catastrophizing children and *high* catastrophizing parents demonstrated the greatest disability. These findings provide strong rationale for continued work to elucidate the impact of parent and child beliefs on pain outcomes.

In addition to catastrophizing, pain-related injustice – an appraisal cognition comprising elements of the severity of loss, blame, unfairness, and irreparability[40] – has been identified as an important cognitive-emotional factor for adults[29,38,40] and, more recently, for children with pain[22]. High injustice perceptions are associated with elevated pain behavior, psychological distress, and poor functional outcomes in adults[29,38,40,40] and with elevated pain intensity, catastrophizing, and poorer physical, emotional, social, and school functioning in children[22]. To our knowledge, no study has investigated the pain-related injustice perceptions of important confidants (e.g., parent, spouse) to the pain sufferer. Drawing from the catastrophizing literature, one might expect that parents of children with chronic pain may

develop appraisals related to the unjust nature of their child's pain (i.e., "my child should not have to live this way"). The prominent role of parents in the lives of children and their influence on children's overall belief systems[13,34] – including general justice beliefs[7] – argue for research examining parental pain-related injustice perceptions. Moreover, previous studies highlighting discordance in child-parent ratings of pain[10,49], functioning[5,10], and catastrophizing[21,35], and its impact on pain treatment and outcomes, suggest the need for similar research examining the degree and impact of discordance in child-parent injustice perceptions. The current study sought to gain a better understanding of pain-related injustice perceptions of children with chronic pain and their parents who care for them. Our specific aims were to investigate: 1) the relationship between child and parent pain-related injustice perceptions and 2) the extent to which child-parent concordance of these perceptions was associated with pain and functional outcomes.

Materials and Methods

Sample

The participants for this study were dyads of pediatric pain patients and one of their caregivers attending a Midwestern tertiary care, interdisciplinary pediatric pain clinic between January 2014 and March 2017. Each "dyad" comprised a patient and his or her caregiver. Patients are referred to the clinic by their primary care provider or specialist due to persistent pain related to sports activity, injury, surgery, chronic disease, or psychogenic causes. Patients attending the clinic may receive anesthesiology services, physical therapy, psychological services, and/or other services to manage chronic pain. Inclusion criteria for participation in this study were that the patients had to be between the ages of 8 and 18, attend the pain clinic for at least one appointment, have no developmental delay that prevents self-report questionnaire completion, and both patient and parent were able to speak and read English. Two hundred and fifty-three patients with a variety of pain conditions and their parents who completed measures during an initial (N=85) or a follow-up (N=168) appointment were included in the final sample. Data from a subset of this sample were analyzed in a previous study [22]; however, that study

focused only on pediatric patients, did not include parents, and had different aims from the current study.

Procedure

This study included clinical data collected from patients and their parents during normal clinical appointments as a routine part of the clinic's pain assessment program. Initial clinic appointments last approximately 3 hours and often include a nurse, anesthesiologist, physical therapist, and pain psychologist. Dyads concurrently completed the electronic forms assessing perceived injustice, pain, stress, functioning, and quality of life at the beginning, and on rare occasion, end of their clinic appointments. Clinical personnel were available to answer any questions about the forms. Clinical personnel then de-identified all data to ensure compliance with HIPAA and PHI standards. All study procedures were approved by the Indiana University Institutional Review Board.

Measures

Perceptions of Injustice about Pain (Child and Parent Versions)

Perceptions of injustice were assessed using two different versions of the Injustice Experiences Questionnaire (IEQ)[38]. Patients filled out the IEQ-Child (IEQ-C) measure, and parents filled out the IEQ-Parent about Child (IEQ-PC) measure. Both versions are 12-item measures assessing feelings of injustice related to one's own pain (IEQ-C) or one's child's pain (IEQ-PC). Using a 5-point Likert scale ranging from 0 ("never") to 4 ("all the time"), patients and their parents rate how frequently they identify with statements such as "I should not have to live this way" (IEQ-C) or "My child should not have to live this way" (IEQ-PC). For this study, the instructions from the original measure were modified so that participants were directed to respond to items in reference to their own pain (IEQ-C; for child participants) or their child's pain (IEQ-PC; for parents). Item values are summed using the Likert ratings to calculate the total score for injustice perceptions. The current study analyzed total score responses in line with Sullivan and colleagues'[38] recommendations. The total score has shown good reliability and validity across several adult chronic pain samples[38,40,42] and more recently in children with chronic pain[22, Baert et al., ISPP poster presentation, September 2017]. The IEQ-C and IEQ-PC demonstrated good internal consistency ($\alpha=0.92$, $\alpha=0.89$, respectively) in the current study.

Pain Intensity

Patients rated their current pain using a numerical rating scale (NRS-11) ranging from 0 (“no pain at all”) to 10 (“most pain ever”)[47].

Stress

Patients rated their current stress (“What is your current stress level right now?”) using a numerical rating scale (Stress NRS-11) ranging from 0 (“no stress at all”) to 10 (“most stress ever”)[16].

Functional Disability

The level of functional disability for each patient was measured using the Functional Disability Inventory (FDI)[48]. The FDI is a 15-item self-report questionnaire that asks respondents to rate their difficulty performing daily tasks, such as walking up stairs and walking to the bathroom, on a scale of 0 (“no trouble”) to 4 (“impossible”). The items are summed to create a total score, with higher scores reflecting greater functional disability. The FDI was found to be reliable and valid in several different pediatric pain populations[4,17,44]. The FDI showed good internal consistency ($\alpha=0.89$) in the current sample.

Quality of Life

Patients’ quality of life was assessed using the Pediatric Quality of Life Inventory (PedsQL) – Generic Core Scales[43]. The measure includes 23 self-report items about physical problems (“It is hard for me to run”), emotional problems (“I feel angry”), social problems (“Other kids tease me”), and school problems (“It is hard to pay attention in class”), each of which is rated on a 5-point Likert scale ranging from 0 (“never”) to 4 (“almost always”). All items are reverse scored and transformed into a 0 to 100 scale. The PedsQL total score is calculated by averaging the items, with higher scores reflecting better quality of life. The PedsQL has frequently been used in studies of pediatric chronic health conditions, which have shown the measure to be reliable and valid[26]. The PedsQL showed good internal consistency ($\alpha=0.93$) in the current sample.

Statistical Analyses

Assumptions of normality were assessed prior to conducting the analyses, and no violations were indicated. Zero-order correlations were calculated to assess the bivariate relationships among all study variables. T-tests were used to examine differences between IEQ-C and IEQ-PC responses within each dyad. Child-parent dyads were then categorized into one of four categories based on the degree of concordance or discordance between IEQ-C and IEQ-PC scores. We first separated the dyads based on the concordance or discordance of each dyad's injustice perception scores. In the overall sample, the mean difference between child (IEQ-C) and parent (IEQ-PC) scores was -6.29 ($SD=12.19$). To be classified as concordant, dyads needed to have a difference score within 1 standard deviation (SD) above or below this sample mean. Thus, difference scores for concordant dyads could range from -18.48 to 5.90. Dyads with difference scores more than 1 SD above or below the sample mean were labeled as discordant. Following this initial classification, concordant dyads were further classified as concordant-high or concordant-low. Concordant dyads in which both child and parent scored over 18 (suggested clinical cutoff of 19) on their respective IEQ measures[30] were labeled *concordant-high*. Concordant dyads in which both child and parent scored below 18 were labeled *concordant-low*. Discordant dyads were likewise divided into two groups. Discordant dyads were labeled *discordant high child (C) – low parent (P)* if the child's IEQ score was higher than the parent's IEQ score. Discordant dyads in which the child's IEQ score was lower than the parent's IEQ score were labeled *discordant low child (C) – high parent (P)*. After categorizing parent – child dyads into one of these four groups, we used one-way ANOVAs to examine differences in pain intensity, functional disability, and quality of life across groups. Post-hoc analyses were used to examine significant differences.

Results

Sample descriptives are summarized in Table 1. The sample was predominately female (75%) and White (83%), with an average age of 14.1 years ($SD=2.25$). Almost half of the patients had multiple pain conditions (45.8%). Descriptive information and bivariate correlations among variables are detailed in Table 2. Dyads who completed the forms at their initial ($N=85$) clinic appointment did not significantly differ from dyads who completed the forms at a follow-up appointment ($N=168$) on child-parent IEQ difference score ($p=.12$), pain intensity ($p=.98$), stress ($p=.65$), functional disability ($p=.57$), or quality of life ($p=.72$).

Parents reported significantly higher injustice scores than children ($t(254)=8.24, p<.01, d=.57$). Of 253 child-parent dyads, 175 (69%) showed concordant injustice scores. Of these dyads, 137 (78%) endorsed high injustice perceptions (Child and Parent IEQ score ≥ 18) and 38 (22%) endorsed low injustice perceptions (Child and Parent IEQ score < 18). Eighty of the dyads (31%) had discordant injustice scores, with 42 dyads characterized as *discordant high C – low P* (child IEQ score greater than parent IEQ score), and 38 dyads characterized as *discordant low C – high P* (child IEQ score less than parent IEQ score). Child-parent IEQ difference scores were not significantly correlated with child age ($p=.40$), nor did dyad category significantly differ by child age ($p=.25$). Group descriptives are reported in Table 3.

One-way ANOVAs identified significant dyad category differences in child-reported pain intensity ($F(3,232) = 2.94, p < .05, \eta^2 = .04$), stress ($F(3,232) = 11.45, p < .01, \eta^2 = .13$), functional disability ($F(3,228) = 13.93, p < .01, \eta^2 = .15$), and quality of life ($F(3,234) = 21.95, p < .01, \eta^2 = .22$). In terms of pain intensity, discordant high C – low P dyads reported the highest pain intensity of the four groups, and significantly higher pain intensity than discordant low C – high P dyads ($MD = 1.77, p < .05$, Figure 1). Pain intensity did not significantly differ between additional dyad categories ($p > .05$).

In terms of stress, discordant high C – low P dyads likewise reported the highest stress of the four dyad categories, and significantly higher stress than discordant low C – high P dyads ($MD = 3.34, p < .01$, Figure 2), concordant-low dyads ($MD = 3.25, p < .01$), and concordant-high dyads ($MD = 1.98, p < .01$). Reported stress did not significantly differ between all other groups ($p > .05$).

Discordant high C – low P dyads also reported the most functional disability of the four dyad categories, and significantly more disability than concordant-low dyads ($MD = 13.28, p < .01$) and discordant low C – high P dyads ($MD = 11.79, p < .01$, Figure 3). Dyads in the concordant-high group reported the second most functional disability and significantly more functional disability than concordant-low ($MD = 9.03, p < .01$) and discordant low C – high P dyads ($MD = 7.54, p < .01$). Functional disability did not significantly differ between concordant-low and discordant low C – high P dyads ($p > .05$).

Discordant high C – low P dyads reported the poorest quality of life of the four dyad categories, and significantly worse quality of life than concordant-low dyads ($MD = -29.38, p < .01$, Figure 4), discordant low C – high P dyads ($MD = -23.64, p < .01$), and concordant-high dyads ($MD = -9.44, p < .05$). Dyads in the concordant-high group reported the second worst quality of life and significantly poorer quality of life than concordant-low ($MD = -19.93, p < .01$) and discordant low C – high P dyads ($MD = -14.19, p < .01$). Quality of life did not significantly differ between concordant-low and discordant low C – high P dyads ($p > .05$).

Discussion

Overall, parents reported higher pain-related injustice perceptions (about their child's pain) than children. The majority of children and parents indicated concordant injustice perceptions, with those indicating discordant perceptions equally split between low child(C) – high parent(P) and high child(C) – low parent(P) dyads. Both the degree (concordant vs. discordant) and direction (discordant low C – high P vs. discordant high C – low P) of congruence between child and parent injustice perceptions were associated with several child-reported pain outcomes.

Dyads where the child endorsed elevated injustice perceptions (concordant high and discordant high C – low P) were characterized by higher pain, stress, and disability, and poorer quality of life as reported by the child, compared to dyads where the child endorsed lower injustice perceptions. These findings align with research suggesting that negative pain appraisals are related to poor pain outcomes in children[18,21,22,25,35,36,44]. Catastrophizing, in particular, has been associated with negative outcomes including increased pain behaviors and depressive symptoms, and decreased functioning[21]. Although pain-related catastrophizing and injustice have some features in common, recent research in pediatric chronic pain indicates injustice perceptions predict unique variability in pain intensity, disability, and emotional-, social-, and school-related functioning, over and above that of catastrophizing[22]. For example, children who endorse beliefs such as “most people don’t understand how severe my condition is” (item 1 on IEQ-C) or “I worry my condition is not being taken seriously” (item 8 on IEQ-C) may feel estranged from peers and withdraw socially. These pediatric findings mirror those from the adult literature wherein injustice perceptions are associated with worse pain and disability, higher catastrophizing, and more depressive symptoms[29,31,37,38,40].

Parents play a unique role in the foundation of their children's justice beliefs[7], as well as their conceptualizations of and responses to pain[23,24]. The way parents think about and respond to children's pain appears to be especially important[23]. For example, parental catastrophizing about their child's pain is associated with greater child pain intensity, somatic complaints, catastrophizing, school absences, and functional disability[19,12,20,25,46]. Our results suggest pain-related injustice perceptions operate similarly. Parents who endorse beliefs such as "most people don't understand how severe the [my child's] condition is" (item 1 on IEQ-PC) or "my child should not have to live this way" (item 4 on IEQ-PC) may respond differently to their child's pain than parents who do not endorse those beliefs. Overly protective or solicitous parental responses are particularly detrimental and are associated with, among other things, increased impairment and symptom complaints in children[3,14,18,33,36]. Parents who frequently think of their child's pain as irreparable (i.e., "I feel that this has affected my child in a permanent way" – item 6 on IEQ-PC) may be particularly likely to engage in such protective or solicitous behaviors. Likewise, parents who believe that "most people don't understand how severe my child's condition is" may inappropriately limit their children's activities out of fear of causing further harm. Such parents may also engage in an over-abundance of pain check-ins (e.g., "How is your pain?" "Are you doing too much?"), thus drawing their children's attention to pain and away from valued life activities[45]. However, we did not measure parental responding in the current study, so these hypotheses remain to be tested.

A particularly novel aspect of our study was its focus on the discrepancy between parent and child injustice appraisals. Our findings suggest that pain and functional outcomes for children are associated with the degree to which children and parents share the same justice-related perspective about pain. Both dyad groups containing children with high injustice perceptions had poor pain outcomes. However, dyads in which children hold higher injustice appraisals than their parents reported the poorest outcomes. As above, these findings align with the catastrophizing literature in which high catastrophizing child – low catastrophizing parent dyads report greater child disability[21,35] and depressive symptoms[21] than other dyads. Child-parent discrepancies in injustice perceptions may engender feelings of invalidation in the child – that their parent is not taking their pain seriously – and lead to maladaptive behaviors intended to communicate the severity of their condition. Indeed, injustice perceptions are associated with heightened displays of pain behavior[39] and consequent adverse

outcomes[27,28] among adults with pain. Of note, discordant high C – low P dyads had an average parent IEQ score above the suggested cutoff of 19[30] – accordingly, although children within this dyad category endorsed higher injustice than their parents, parents still on average endorsed clinically elevated injustice. Future research could examine if and how these dyads differ from high C – low P dyads where parents do not score above the cutoff. The apparent importance of child-parent concordance notwithstanding, the fact that the best outcomes were observed for dyads where the child scored low on injustice, along with the fact that bivariate correlations between injustice and outcomes were stronger for the IEQ-C than IEQ-PC, suggest that child perceptions may be the primary driver of these relationships.

The current findings have several clinical implications. Scholars have begun discussing interventions for pain-related injustice perceptions in adults[31,40]. The current study and those that preceded it[22, ISPP poster presentation, September 2017] suggest that children and adolescents should be included in these discussions. Our findings also highlight the important role of parents in this context and suggest that injustice-focused interventions for pediatric pain should include a parental component. Our findings further suggest that parental injustice perceptions interact with child perceptions to exacerbate pain outcomes for the child. Discordant injustice perceptions, particularly in the case of high child – low parent combinations, may complicate treatment. Fisher and colleagues[8] found child-parent agreement on treatment goals was associated with lower pain intensity and may be an important treatment process to consider. Relatedly, disparate child-parent injustice views may influence their level of agreement on treatment goals and, consequently, treatment success. For concordant high dyads, psychoeducation about and cognitive restructuring of pain-related injustice appraisals may be a first step. Acceptance-based approaches that emphasize values-based living, even while having thoughts about the unfairness of being in pain, may also prove beneficial. For high C – low P dyads, a brief intervention to discuss and bring awareness to the discordance in injustice perceptions may serve to lessen the negative impact on outcomes; such an intervention might even be incorporated into an initial clinical evaluation. Parental training in empathic and validating responding may be an additional treatment component.

Several study limitations should be considered. The cross-sectional nature of the data limits conclusions that can be drawn about the relationship between perceived injustice and pain

outcomes. Additionally, all constructs were assessed using self-report measures, which are susceptible to problems of common method variance and negative response set; these measures are also predicated on the assumption that participants can think about and accurately report on their psychosocial experiences and pain outcomes. Also, patients were predominately white and female, from one clinic, which may limit the generalizability of these findings. We did not collect detailed information about parents/guardians, such as medical history, caregiver status (primary vs. secondary), or socioeconomic status, which may be relevant in this context. Gender of the primary caregiver is also potentially relevant, as the injustice perceptions of mothers vs. fathers may have differential implications for child outcomes. Furthermore, we did not collect information about length of diagnosis or number of clinic appointments attended, which may influence pain-related injustice perceptions and outcomes.

Future research is needed to replicate these results and continue to examine the extent to which parent and child injustice perceptions impact the pain experience for children and adolescents. Given that research on injustice perceptions in pediatric pain is in its early stages, many factors remain to be explored. The relationships among parent and child injustice perceptions, parental responding, and child pain behaviors have yet to be investigated. Studying this relationship may help elucidate mechanisms by which injustice leads to poor outcomes. Similarly, investigating injustice perceptions of other central figures – including both parents, other family members, teachers, and friends – may yield new insights about the pediatric pain experience that are relevant to clinical outcomes. At the very least, given that much of the pediatric literature focuses on mothers, extending the focus to fathers represents a clear next step in this line of inquiry. Also, exploring the dimensions of pain-related injustice (i.e., blame/unfairness vs. severity/irreparability of loss), their concordance among parent and child, and their unique and collective impact on the child's pain experience may lead to better targeted and more effective interventions. Prospective studies in adults indicate perceived injustice is a risk factor for poor rehabilitation outcomes[38,41] and decreased likelihood of returning to work[9,38]. Future research is needed to explore if similar patterns (i.e. poor rehabilitation outcomes, decreased likelihood of returning to school) exist for children with chronic pain. Lastly, precursors to the development of pain-related injustice perceptions have yet to be explored. Factors such as pain-related stigmatization and violation of just-world beliefs may

precede the development of pain-related injustice perceptions. Future research is needed to elucidate such precursors.

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Figure 1. Comparison of pain intensity across child-parent dyads.

Figure 2. Comparison of stress across child-parent dyads.

Figure 3. Comparison of functional disability across child-parent dyads.

Figure 4. Comparison of quality of life across child-parent dyads.

Table 1. Demographic Characteristics

Table 2. Zero-order correlations

Table 3. Means and SDs of Study Variables by Child-Parent Injustice Dyad Group

Figure 1.

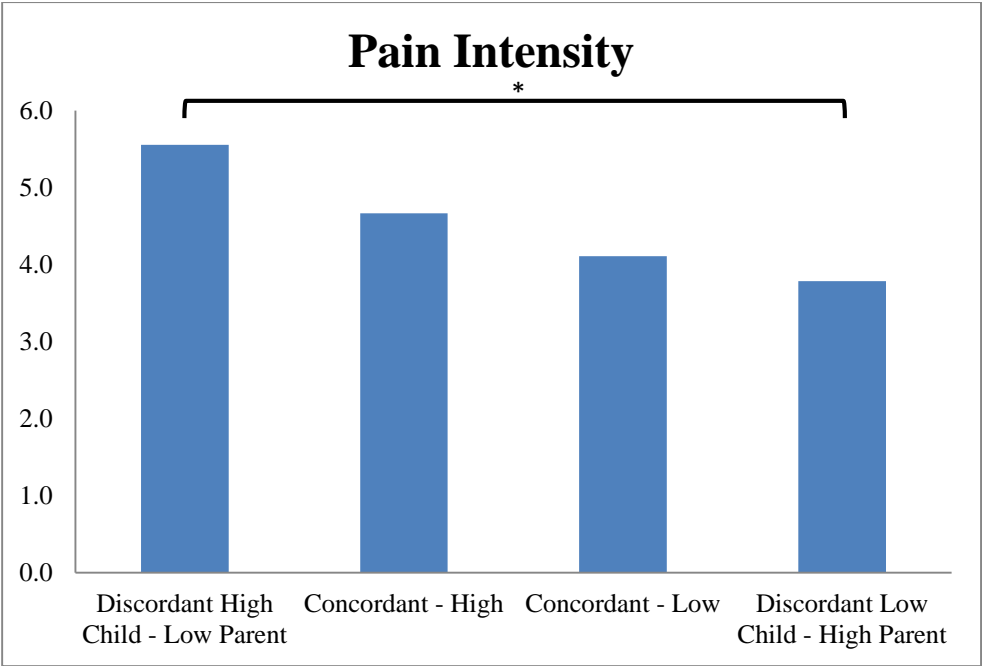


Figure 2.

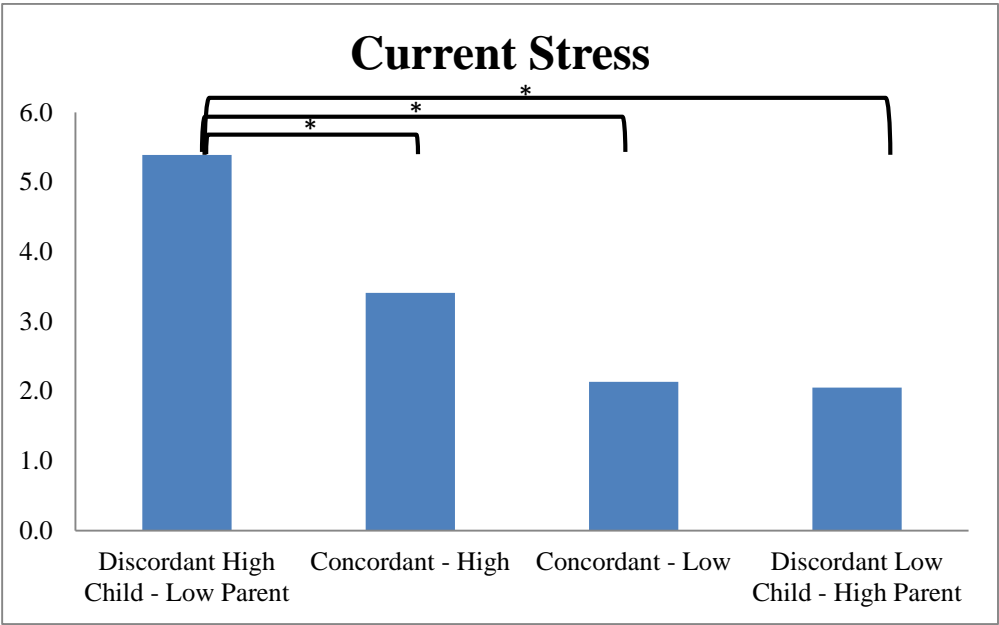


Figure 3.

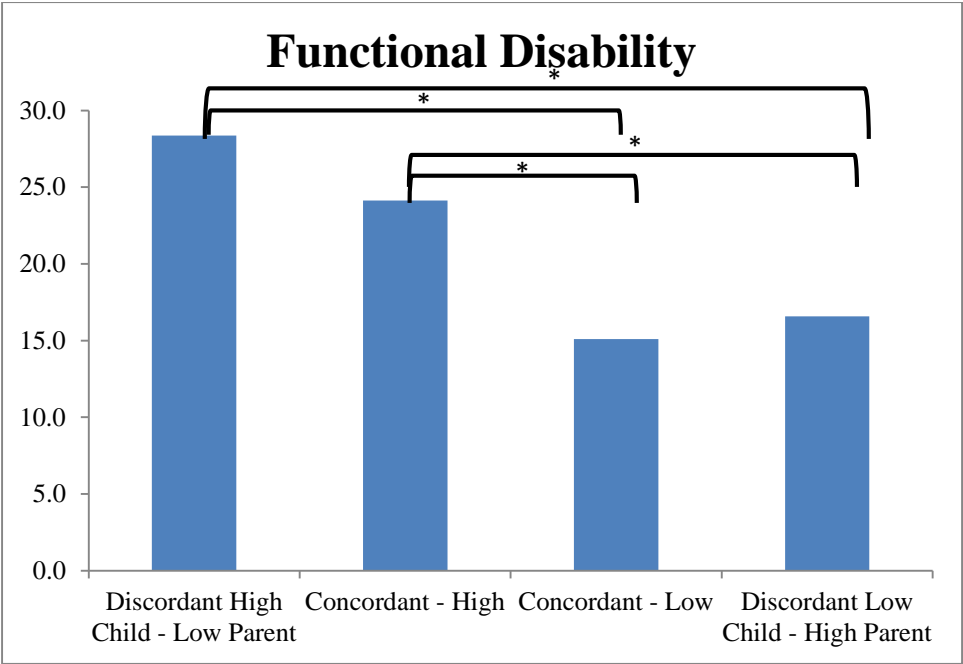


Figure 4.

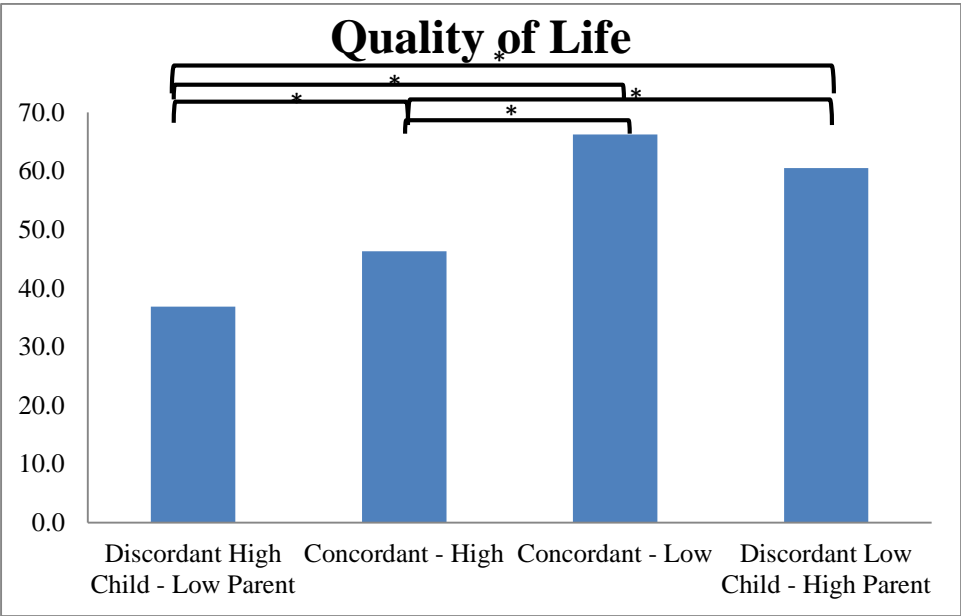


Table 1. Demographic Characteristics

N=253		n (%)
Sex		
	Male	64 (25.3)
	Female	189 (74.7)
Race		
	Caucasian	211 (83.4)
	African-American	10 (4.0)
	Multi-racial	2 (0.7)
	Refused to report	30 (11.9)
Age		
	8-10 years	18 (7.1)
	11-13 years	56 (22.1)
	14-16 years	137 (54.2)
	17-18 years	42 (16.6)
Pain Condition		
	Complex regional pain syndrome	19 (7.5)
	Migraine/headache	7 (2.8)
	Neuropathic	1 (0.4)
	Musculoskeletal	14 (5.5)
	Visceral	28 (11.1)
	Multiple pain diagnoses	116 (45.8)
	Chronic fatigue syndrome	1 (0.4)
	Not reported	67 (26.5)

Table 2. Zero-order correlations

Variable	Mean	SD	1	2	3	4	5
1. IEQ-C	18.94	11.98					
2. IEQ-PC	25.50	9.77	.40**				
3. Pain Intensity (0-10)	4.46	2.82	.32**	.20**			
4. Stress (0-10)	3.20	2.98	.39**	.13*	.45**		
5. FDI	22.06	11.45	.57**	.33**	.55**	.47**	
6. PedsQL-C	50.14	20.08	-.65**	-.34**	-.33**	.47**	-.74**

* $p < .05$, ** $p < .01$

Abbreviations: IEQ-C, Injustice Experiences Questionnaire-Child; IEQ-PC, Injustice Experiences Questionnaire-Parent about Child; FDI, Functional Disability Inventory; PedsQL-C, Pediatric Quality of Life-Child

Table 3. Means and SDs of Study Variables by Child-Parent Injustice Dyad Group

Variable	Group Mean (SD)			
	Concordant-High	Concordant-Low	Discordant High Child - Low Parent	Discordant Low Child - High Parent
IEQ-C	21.63 (10.07)	7.00 (4.68)	32.33 (8.66)	8.18 (6.74)
IEQ-PC	28.50 (7.78)	12.71 (4.17)	20.36 (8.50)	33.13 (6.63)
Pain Intensity (0-10)	4.67 (2.73)	4.11 (2.78)	5.56 (2.71)	3.78 (2.87)
Stress (0-10)	3.41 (2.99)	2.14 (2.21)	5.39 (3.06)	2.05 (2.25)
Functional Disability	24.12 (10.61)	15.09 (9.40)	28.37 (11.73)	16.58 (10.81)
Quality of Life	46.31 (17.64)	66.24 (20.74)	36.87 (18.90)	60.51 (16.09)